

Privacy and Responsible Information Sharing for the Western Australian public sector discussion paper

Executive Summary

National Disability Services (NDS) WA is pleased to provide comment on the WA State Government Privacy and Responsible Information Sharing for the Western Australian public sector discussion paper.

NDS broadly supports arrangements for the provision of more timely, accurate data relevant to the provision of specialist disability care and also mainstream services such as employment services, with adequate data protections. We support in principle the drive for data sharing / pooling across Government to better inform decision making that impacts on the social and economic participation of Western Australians with disability, those eligible for the National Disability Insurance Scheme (NDIS) and the many people with disability outside the Scheme who also require mainstream services.

However, it is critical that the draft legislation is informed and shaped by all affected parties including not for profit organisations such as WA disability service providers through a comprehensive engagement and consultation process where models can be tested and refined. These organisations should be provided extensive opportunity to co-design the proposed regulatory and legislative framework.

We are also supportive with the State Government's desire to be consistent with other State and Territory legislation and the Federal Government's proposed information sharing legislation, and in principle, the approach outlined in the discussion paper which heavily favours the "5 Safes" approach as the basis of its information-sharing framework, a set of criteria that must be satisfied before the relevant organisation can share information with another organisation.

NDS welcomes the opportunity to work with the WA State Government and all Australian governments so that the proposed framework for data sharing and release is used to support the disability sector in its development and growth (particularly to inform markets decision making in the NDIS), and ultimately to improve the social and economic participation of people with disability, their families and carers.

Background

The WA State Government committed to introducing legislation governing the privacy of personal information and information sharing in the WA public sector. As a first step towards fulfilling that commitment, it has released a discussion paper seeking submissions with respect to the framework, form and content of the proposed privacy legislation.

Currently, WA is one of only two States and Territories that does not have legislation governing the privacy of personal information handled by the WA public sector – a gap that, given the Federal privacy legislation does not apply to the WA public sector, is significant.

Privacy and information-sharing in the WA public sector are currently governed by a patchwork of common law principles and entity-specific legislation and regulation. There are no over-arching legislative principles governing the handling of personal information in the WA public sector; no body with oversight of such handling.

Comments

The discussion paper proposes that the proposed privacy legislation will impose both privacy and information-sharing regimes for the WA public sector.

No commitment is given as to the framework or form of the proposed privacy legislation at this stage, but the discussion paper indicates that important considerations of the proposed privacy legislation are the following:

- **Privacy Principles:** Unsurprisingly, the discussion paper highlights a desire to adopt laws consistent with those in force at the Federal level and in other States and Territories. In particular, the flexibility offered by the adoption of a set of overarching privacy principles such as the Australian Privacy Principles contained in the Privacy Act 1988 (Cth). NDS supports this position.
- **State Privacy Body:** The application and enforcement of the proposed privacy legislation would be the responsibility of an independent privacy oversight body led by a WA Privacy Commissioner. The extent of its powers remains to be seen and NDS will provide further comment when these powers are clearly articulated.
- **Facilitation of appropriate information-sharing:** To provide certainty to the WA public sector and the public, the proposed privacy legislation is likely to outline certain activities for which information can be shared (e.g. for the efficient delivery of government services); prohibit information-sharing for certain activities (e.g. for direct marketing); and otherwise outline a process by which information sharing can be approved.

As to the latter, and consistent with other State and Territory legislation and the Federal Government's proposed information sharing legislation, the discussion paper heavily favours the "5 Safes" approach as the basis of its information-sharing framework. The "5 Safes" are a set of criteria that must be satisfied before the relevant organisation can share information with another organisation. NDS supports these in principle.

- **Chief Data Officer:** Information-sharing extends beyond privacy considerations. To support the WA public sector in adopting best practice standards for information-sharing, including for the appropriate use of technology, the proposed privacy legislation is likely to create the role of Chief Data Officer, reporting either to the responsible Minister or to the WA Privacy Commissioner and supported by the recently established Office of Digital Government.

The discussion paper strongly suggests that the WA Government is in principle keen to align to the national approach. NDS broadly supports this direction on the basis that it would likely lead to better data sharing (more timely accurate data and better data linkage, especially with State data) that will enable an assessment of policy, support research and importantly for NDS members promote open sourcing data assets relating to supply / demand of disability services.

NDS agrees that the data collected by the public service is largely an untapped asset muddled around a complex array of common law and numerous statutes that govern and regulate the confidential sets of information that government holds. Proposed future legislation is an opportunity for more accountability and transparency around what and where the government shares data but must be developed and designed in consultation with private and not for profit organisations including those operating in the disability sector.

The discussion paper indicates that the proposed privacy legislation will apply to organisations beyond those which fall within the definition of the public sector under the Public Sector Management Act 1994 (WA) and could include organisations such as local governments, public universities, and State Government trading entities.

However, the practical reach of the proposed privacy legislation can be expected to extend far beyond this to those non-government organisations and entities whose dealings with those covered by the proposed privacy legislation involve the provision or receipt of personal information. Such non-government organisations and entities can expect to see clauses requiring compliance with the proposed privacy legislation feature in future contracts with the WA public sector. This should not lead to an increase in onerous processes that increases the administrative burden on not for profit organisations.

NDS is of the view that the draft legislation should be informed and shaped by all affected parties including not for profit organisations such as WA disability service providers through a comprehensive engagement and consultation process where models can be tested and refined. It is critical that these organisations are provided extensive opportunity to co-design the proposed regulatory and legislative framework. This is particularly important in reference to the specific aspects of the proposed privacy legislation that the State Government is seeking views about including: -

- the suitability of the Australian Privacy Principles for WA;
- how breaches of privacy should be managed, including the form of response to privacy breaches;
- the role and powers of a WA Privacy Commissioner and Chief Data Officer;
- whether the State Government should facilitate the sharing of information outside of the WA public sector and, if so, under what conditions; and
- what steps need to be taken by the State Government to support the roll-out of the proposed privacy legislation.

Desired Policy Outcomes

NDS supports in principle the drive for data sharing / pooling across Government to better inform decision making that impacts on the social and economic participation of Western Australians with disability, those eligible for the NDIS, about 48,000, and more than 360,000 people outside the NDIS. This must be underpinned by the following:

- Clear safeguards and guidelines for where data can be shared and with who, along with greater consideration for what constitutes confidential and sensitive information.
- The proposed 'privacy and responsible information sharing' legislation for data collected by the public service should lead to quicker decisions and less duplication across State Government departments and agencies.
- The need for clear visibility of how data is handled once submitted to government as currently there is no clear way of tracking where it went as well as transparency around data breaches.
- Consistency around classification of highly sensitive commercial information applied across the Government sector.
- Management and resourcing a governance framework including the monitoring of data sharing by staff including those with specialist skills as data analysts.

Improvements to agency data use and sharing is best realised within a framework of openness, supported by appropriate agency capability and data security arrangements, and underpinned by a robust oversight regime.

The challenge facing Government is how it can use the data it collects in more effective ways while also maintaining privacy protections for the individual, which is of paramount importance. This does not have to be a choice or a trade-off. However, arguably the current legal framework can be updated to better advance these twin objectives. To ensure acceptance of any new approaches, it will be important that they be developed in an open and consultative fashion.

NDS highlights that irrespective of the legal regime that applies to specific data, agency culture has a significant impact on the use and availability of data within government. Agencies regularly point to concerns such as privacy or security, but the real issue can be a reluctance to make data available. This reluctance can be driven by a concern for how an agency's information will be used by other entities (loss of control), concerns about the cost of changing systems and processes to enable sharing of data, and concerns about exposure to criticism and/or legal risk. Public servants are primarily focussed on the actions and performance of their own agency, whereas sharing is likely to be for the purposes of other agencies. In addition, public servants have a positive obligation to control access (the need to know principle), which makes increasing accessibility counter-cultural.

From the perspective of those who own the data and consume government services, the same information might be provided by an individual to multiple separate agencies, for multiple purposes. Individuals might prefer to have the option to provide the information only once, on the basis that it can then be shared between particular agencies for specified purposes. Relevant and related information that could enable quicker and higher quality decision-making about the individual or about their community may be held by other agencies again. Citizens may be both mistrustful of government's ability to handle their data and highly critical that government does not operate in a joined up way to provide them with quality services.

Disability data

In this submission, NDS also provides specific comments around the focus on access to public data, especially access to State disability data as well as Commonwealth data relating to the NDIS, as an enabler of sector development, innovation, and growth as well better and more accountable implementation of the National Disability Strategy.

Poor data governance and access to data in relation to State and Federal stewardship of the new disability marketplace and other disability services directly funded by governments for the purposes of research, industry analysis, and to support disability service providers to plan remains a critical issue for the sector. This is also the case with holistic reporting with the implementation of the National Disability Strategy at State levels and with progress in improving the social and economic participation of people with disability across the six policy areas of the Strategy.

CASE STUDY

For example, an ongoing study by the Public Sector Research Group at UNSW illustrates how poor data governance is an impediment for disability service providers supporting NDIS participants to increase Australia's relatively poor (OECD) performance on the labour market participation of people with disability.

The Data Governance and the NDIS study has mapped the collection and use of data in four key services involved in building pathways to work and boosting the workforce participation of people with disabilities in Victoria.

The services are:

- NDIS - federal government and agency
- Disability Employment Services (DES) - federal government
- vocational education and training (VET) - state government with a national regulator
- Jobs Victoria Employment Network (JVEN) - state government

The early findings which can provide some lessons for consideration in the shaping of WA legislation are:

- While all four services under examination are charged with equipping people with disabilities to participate in the labour market, there seems to be no agreed definition of disability or consistent eligibility criteria across the services.
- The study has not found any coordination of data governance, collection and use in government across the four services.
- Software systems for collecting data in each service are incompatible, making data sharing and integration across services difficult.
- The only place data on these services can be combined is within service providers holding multiple government contracts, but this is not a straightforward process. For many, the cost of retrieving and combining data from different software systems mandated by different arms of government is prohibitive, involving creating, managing and populating an in-house database and analysing the data. Most organisations holding multiple contracts effectively operate each service as a separate business, although they claim leverage on combined services in bidding for government work. Large providers who can afford to combine data gain a significant competitive advantage.
- The primary purpose of data collection across all four services seems to be performance measurement to meet contractual obligations and/or to trigger payments, not performance improvement.

Considerations for WA privacy-shared data legislation

- There should be agreed definitions of disability or consistent eligibility criteria across the range of mainstream and NDIS services.
- There must be supporting investment in the coordination of data governance, collection and use in government across all services. There will be significant costs associated with establishing and maintain shared data sets and systems which must be considered in the implementation of proposed legislation. The cost of retrieving and combining data from different software systems mandated by different arms of government is prohibitive, involving creating, managing and populating an in-house database and analyzing the data. Most organizations holding multiple contracts effectively operate each service as a separate business, although they claim leverage on combined services in bidding for government work. This is not a straightforward process.
- Ensuring software systems for collecting data in each service are compatible, making data sharing and integration across services easy and seamless.
- Service providers holding multiple government contracts, often large providers, can afford to combine data and may gain a significant competitive advantage over smaller organisations.
- The primary purpose of data collection across all services seems must focus on performance improvement not just performance measurement to meet contractual obligations and/or to trigger payments.

Consideration of specific mechanisms

In cases involving particularly sensitive information, where sharing is nonetheless in the public interest, it may be appropriate to develop specific legislation governing the activity to ensure the necessary degree of transparency and to provide appropriate safeguards. In some circumstances, it may also be appropriate to include an obligation to share information openly in legislation. This goes beyond allowing for sharing, to positively requiring such sharing.

Other jurisdictions offer examples of useful, appropriately-designed data sharing provisions, such as dedicated family violence sharing legislation that permits identified agencies to share information in order to support integrated responses to high risk family violence cases. For example, the Crimes (Domestic and Personal Violence) Act 2007 (NSW) allows an agency to disclose personal information and health information about a threatened person and any person that the agency reasonably believes is a cause of the threat (the 'threatening person') to a central referral point or a local co-ordination point where an agency believes on reasonable grounds that a person is subject to a domestic violence threat. The legislation applies to any threats to the life, health or safety of a person that occur because of the commission or possible commission of a domestic violence offence.

Another example in New South Wales is Chapter 16A of the Children and Young Persons (Care and Protection) Act 1988 (NSW). This positively authorises, encourages or requires agencies that have responsibilities relating to the safety, welfare or well-being of children and young persons to provide and receive information.

Conclusion

NDS broadly supports proposed arrangements for the provision of timely, accurate data relevant to the provision of specialist disability care and also mainstream services such as employment services, with adequate data protections.

The current legislative framework for managing data within Government was conceived at a time when paper was the predominant means of conducting business with Government. The opportunities to use data to improve citizens' lives were limited by the capacity of individual public servants to process and analyse huge volumes of written material. Though legislative amendments have kept pace with technological developments in some cases — the technology neutral framework enacted in the Privacy Act in 2014 being one example — it is reasonable to say additional flexibility appears to be required to ensure Government can use and share data in the way the public expects, subject to appropriate safeguards.

The capacity to use and apply data is of a different order than it was when much of the current legal framework was conceived and this capacity is only going to grow into the future. At the same time, budget-pressure, complex policy challenges, the need to improve Government services and the demand for tailored support to individuals are driving a desire by Government to improve how it uses the data it collects. However, citizens remain concerned about the security of the information they give Government and the uses to which that information might be put. Any discussion of data cannot be divorced from a discussion of privacy.

A tiered approach to improving data use and availability may be one option for further investigation. Firstly, more could be done to promote sharing within the existing legal framework, including under the Privacy Act. Secondly, the use of robust de-identification procedures should be encouraged where information cannot otherwise be shared. Finally, the legislative framework could be improved and modernised through reform. Two options would be the introduction of stand-alone data sharing legislation and amendments to the Privacy Act to allow personal information sharing agreements between agencies.

The three tiers are intended to operate in a cascading fashion, if information can be shared at the highest level of the framework (broad based data sharing legislation or personal information sharing agreements) then you do not need to proceed to the next level and so on.

NDS has been a strong advocate for more and better data since the NDIS began. NDIS data could become the best population-based disability database in the world, and it can be linked to other data. At a national level NDS recently welcomed the NDIA's release of a series of data resources as part of the NDIA's first forward plan to publicly release more and better data. The resources will assist service providers to plan, make better assessments of the volume of funded supports by geographical areas and client groups, and give a more accurate picture of opportunities to offer services and supports.

NDS is a founding member of the Democratising Disability Data Coalition – a coalition of disability sector stakeholders that share an aspiration for equitable access to world-best disability services and supports, something that will only be achieved if the disability sector and other stakeholders can interrogate and evaluate outcomes using linked, shared data. If NDIS data were linked with other routine data, surveys and census data the potential to track the impact of the NDIS on disability, social, economic and health outcomes is enormous. It also offers the potential to track the outcomes for people with disability who are not NDIS participants.

A copy of the Mission Statement of the Democratising Disability Data Coalition is appended to this submission for information and sets out the partners' assessment of the current situation and detailed proposals for the democratisation of disability data within appropriate safeguards that are consistent with those proposed in the Federal Data Sharing and Release Legislative Reforms Discussion Paper and the Privacy and Responsible Information Sharing for the Western Australian public sector discussion paper.

NDS looks forward to working with the WA State Government and all Australian governments so that the proposed framework for data sharing and release is used to support the disability sector in its development and growth, and ultimately the social and economic participation of people with disability, their families and carers.

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National Disability Services WA

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APPENDIX 1

DEMOCRATISING DISABILITY DATA COALITION MISSION STATEMENT

Our purpose

To achieve safe and secure access to disability data and statistics to provide the evidence needed to optimise services and policy to facilitate better lives of Australians with disability, their families and carers.

Who are we?

A coalition of Australian researchers and stakeholders in the disability sector committed to capitalising on data related to disability so we learn from practice and continually refine services and policy to achieve better outcomes.

Our coalition includes academics and universities; disability advocacy organisations; disability services and non-government organisations. We welcome individuals and organisations who support our purpose to sign-up to the Coalition.

The [Melbourne Disability Institute](#) (MDI) at the University of Melbourne auspices the secretariat for the Coalition and Professors Bruce Bonyhady (Director, MDI) and Professor Kavanagh (Academic Director) lead the initiative.

Building unity

The key lesson from the campaign to establish the National Disability Insurance Scheme (NDIS) was that unity across the disability sector was essential for success. Our aim is to build unity and champions across the disability and academic sectors, in relation to democratising disability data.

With the campaign for the NDIS, once the sector was united, it was then necessary to build a broad coalition, including governments and key stakeholders within the broader community, because major progress always requires allies and building and maintaining public trust and confidence.

We encourage official statistics agencies to produce broad statistics describing people with disability in Australia and the services to support them, notably using data on participants in the NDIS and the support they receive.

We would welcome organisations and individuals, particularly people with disability, advocacy organisations and other disability sector organisations, to become Members of the Coalition, to work with us to deliver this very important initiative.

Please go to <https://disability.unimelb.edu.au/research/democratising-disability-data> to register as a Member of the Democratising Disability Data Coalition and receive regular updates.

To build public trust and confidence particularly the confidence and trust of all people with disability, their families and carers, we give this commitment:

Our interests in disability data and linking it to other data sets will be always be to increase public good and we will be working with de-identified data so that the privacy of individuals is always respected.

Fortunately, the Productivity Commission has already developed essential protocols under which data collected by governments and other custodians should be shared, in order to maximise its public benefit and protect privacy. These are known as the “Five Safes”¹. The Coalition is committing:

We will operate in accordance with the “[Five Safes](#)” protocols.

How we work

Our ultimate aim is to make key disability data and statistical reporting by statutory agencies available for research. This will include the linkage of disability data to other key datasets, such as medical records, welfare payments and educational attainment through approved data integration authorities at a Commonwealth and State and Territory level.

In order to achieve this objective, we will:

1. Set up a virtual community
2. Meet regularly by telephone hook-up or video conferencing face-to-face as necessary to develop strategies and approaches
3. Write position papers and fact sheets that can be disseminated broadly
4. Engage with governments and the wider community to build support and trust.
5. Make submissions to various inquires, participate in consultations and be a point of contact for agencies seeking advice regarding disability data, and
6. Be externally-facing by participating in public debate about issues relating to disability data, so as to promote its maximum use for public benefit.

In order to refine our proposals and build a wide and deep consensus to present to governments and to key areas within government, we will be holding a Roundtable on Democratising Disability Data at the University of Melbourne on 4 December 2018.

The policy and reform context

In the last decade Australia has undergone major disability policy and service reform. The NDIS is a \$22 billion a year reform and is the most significant economic and social policy reform since the introduction of the original Medicare scheme in the 1970s.

When it is fully implemented in 2021, the NDIS will provide individualised funding packages to purchase services and supports for 460,000 Australians.

The NDIS is already transforming the way disability supports are funded and delivered, but it is inevitable that such a large and complex reform will take time, not everything will go to plan and that it may not necessarily work for everyone.

We want the NDIS to work for all NDIS participants because, ultimately, the NDIS was introduced to make disability supports equitable and fair. It was designed to end the postcode and other lotteries of the old disability system.

The Coalition is committed to the improvement and optimisation of the NDIS and providing high quality evidence to support its implementation, which is designed to achieve the best outcomes for people with disability, their families and carers and to ensure that the NDIS is sustainable.

¹ Productivity Commission 2017 Review of NDIS Costs, p491

The NDIS will also stimulate individual and community capacity building through Information, Linkage and Capacity (ILC) provided through Local Area Coordinators and other avenues.

The National Disability Strategy (2010-2020) also sets out priorities and strategies to address the disadvantage people with disability experience across all aspects of their lives.

In the Productivity Commission's Review of NDIS Costs, last year, the Commission recommended that the NDIA should share de-identified data to trusted researchers by mid-2018². This has not occurred.

The Coalition believes that lack of access to high quality disability data for research, lack of reporting by statistical agencies and practice improvements mean we are unable to learn fully from what has been done so far. Learning by doing through analysis of data will enable disability policy and practice to engage in a process of continuous improvement and optimisation.

Quantitative disability data and the ability to link it to other data sets is essential for policy and practice optimisation, because it provides the large-scale evidence that governments need to change policy settings and which organisations often require to refine and improve their practices.

In addition, qualitative data can play an important role in adding richness and depth, especially when seeking to understand issues facing hard to reach groups and those with the most complex needs.

UN Convention on the Rights of Persons with Disability (UNCPRD)

Australia has been a signatory to the UNCPRD since 2008 and the Optional protocol since 2009.

Article 31 of the UNCPRD states:

States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention. The process of collecting and maintaining this information shall:

- a) Comply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for the privacy of persons with disabilities;
- b) Comply with internationally accepted norms to protect human rights and fundamental freedoms and ethical principles in the collection and use of statistics.

2. The information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties' obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.

3. States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.

The aims of the Coalition therefore align closely with the objectives of the UNCPRD, which recognises that disability data is an essential foundation for disability rights.

It should also be noted that access to data is, ultimately, about power: the power of information. The NDIS was supposed to put people with disability, their families and carers in control and to ensure that they would have the power. So long as the National Disability Insurance Agency (NDIA)

² Productivity Commission 2017 Review of NDIS Costs, p486

refuses to make its data available for research it is undermining one of the core principles on which the NDIS is based.

The Coalition therefore believes that the NDIA should urgently reassess its current stance and work collaboratively with the disability sector and researchers to disseminate its information as widely as possible consistent with the “Five Safes” and governments should make a broader commitment to disability data collection, linkage and dissemination, which could also meet the “Five Safes”.

[The current situation with data](#)

Independent researchers can currently access a range of de-identified data related to disability in surveys conducted by the Australian Bureau of Statistics (ABS) (e.g. Survey of Disability, Ageing and Carers, the National Health Survey), census data, omnibus longitudinal studies (e.g. the Household Income and Labour Dynamics Survey and Longitudinal Study of Australian Children) and in some limited circumstances routine data collected in other sectors (e.g. child protection, social services and welfare).

The Australian Institute of Health and Welfare (AIHW) also holds a National Minimum Dataset on disability services. However, when the NDIS is fully implemented this data will no longer be collected. Various other organisations such as the National Disability Services also collect data such as through their annual market survey.

Recently there have been major developments in the linkage of various different data sources.

The [Multi-Agency Data Integration Project \(MADIP\)](#) is being led by the Australian Bureau of Statistics (ABS) and includes data from the ABS, Australian Taxation Office, Department of Education and Training, Department of Health, Department of Human Services and Department of Social Services; a number of States and Territories link data across different portfolios; and, the [Data Integration Partnership of Australia \(DIPA\)](#) is an initiative of the Commonwealth Government to maximise the use and value of the Government’s data assets through data integration and analysis.

The Centre for Victorian Data Linkage and the Queensland Government Statistician’s Office have become accredited Data Integrating Authorities, which means they will get access to Commonwealth data sets for linkage purposes. The SA-NT DataLink has also received provisional approval to become an accredited Data Integrating Authority. The Victorian Centre is already linking 30 different data sets and so further data integration will now be possible.

Where data on disability is collected and integrated, the combined data provides great insight into important questions about the upsides and downsides of different policy interventions and the benefits, opportunities and risks for people with disability, their families and carers, as different policies are implemented or services are used. This means we can ‘learn by doing’ and adjust and refine what we do to lead to better outcomes in the future. This aligns closely with the NDIA philosophy of ‘Listen, Learn, Build, Deliver’.

The potential of Australia’s disability data

Most if not all countries face a looming crisis in disability supports, as a result of powerful demographic forces (people with disability living much longer and the capacity of communities to provide informal care declining).

Australia is the only country in the world responding to these pressures in a highly systemic and strategic way, through the implementation of the NDIS and the National Disability Strategy.

Once the NDIS is fully implemented, Australia will have the most comprehensive population-based longitudinal database on people with disability in the world. This will be a unique resource for researchers over time is likely to attract some of the best and brightest academics to disability research and create international interest. It will also be a critical resource for governments to inform their reform and policy agendas.

The sooner we start to make this data available for research, the sooner a community of researchers will build. This is likely to start with PhDs and Post-Doctoral Fellows and so take time to reach its potential.

If NDIS data were linked with other routine data and surveys and census data the potential to track the impact of the NDIS on disability, social, economic and health outcomes is enormous. It also offers the potential to track the outcomes for people with disability who are not NDIS participants.

Without access to NDIS data and its integration with other Commonwealth and State and Territory data we will not realise the extraordinary opportunity to make Australia's disability system the best in the world; we are in the dark about how to optimise outcomes for people with disability and deliver a financially sustainable Scheme.

Securing effective data access and linkage

There are six essential steps to democratise disability data.

1. NDIS data

The major hurdle to advancing policy and service-related disability research in Australia is the lack of access for trusted researchers to de-identified NDIS data in a safe and secure environment.

At the moment, NDIS data is held and analysed by the NDIA and only limited findings are presented publicly in annual and quarterly reports. This means that there is a lack of transparency about what is happening in the NDIS. People with disability from whom the data is collected do not know how well the NDIS is delivering on its aspirations.

Likewise, other stakeholders such as State and Territory governments, service providers and local area coordinators are in the dark about how to adapt their practices to achieve better outcomes. This limits the capacity for a process of continuous improvement.

The NDIA is the custodian of NDIS data, not its owner. Its purpose is to serve people with disability so giving access to disability data to participants and their families and for public benefit is both essential and urgent.

The key steps in relation to NDIS data are for the NDIA to:

- Provide detailed information on the data which is being collected by the NDIA, including a data dictionary
- Facilitate access to the NDIS integrated unit-record de-identified data to trusted researchers for approved projects in a safe and secure environment according to the "Five Safes" protocol
- Provide NDIS data (with appropriate identifiers) to data integration authorities such as the Australian Bureau of Statistics, the Australian Institute of Health and Welfare and State and

Territory data linkage units so that NDIS data can be linked to other administrative, census and survey data (including existing integrated datasets such as MADIP) noting that some key data sets which should be linked to the NDIS data, such as child protection data, are collected at the State and territory level

- Follow international best practices on data access and allow those data integrating authorities to determine whether the “Five Safes” are being met, rather than referring every data request back to the NDIA, and
- Work with researchers and the disability sector to ensure that research findings are utilised to inform a process of continuous improvement.

2. *Survey of Disability Ageing and Carers (SDAC)*

The Survey of Disability, Ageing and Carers (SDAC) is an essential data base for disability research and even following the full implementation of the NDIS, it will be vital, because it will provide the most comprehensive source of information on disability in Australia, as it covers all people with disabilities, not just NDIS participants.

The SDAC is aligned with the National Disability Agreement, without being formally part of it. For example, it was as a result of discussions between the Commonwealth and the States and territories that agreement was reached to collect SDAC data every three years, rather than every six years. This has applied since 2009 and the SDAC data has also been expanded to capture additional data that enables progress on the National Disability Strategy to be measured better.

In the years which correspond with the original six-year collection, the ABS pays for the base sample out of its budget. This was the case in 2009 and 2015. In 2015 the Department of Social Services also contributed an additional amount to allow for greater information at the State level.

For the 2018 survey, which is an example of an additional survey reflecting the decision to collect data every three years, 50 per cent of the funding is being provided by the Commonwealth, through the Departments of Social Services and Health, and 50 per cent from the States.

With this year's survey New South Wales, Victoria, Queensland and WA have all contributed their additional funding. This will allow for over-sampling and will therefore provide data at the State level, for these jurisdictions. However, the other jurisdictions have declined to contribute additional funding and so accurate State and Territory level data will not be available for South Australia, Tasmania, the ACT and Northern Territory. This is unfortunate.

SDAC data at the State and territory level will be vital to measuring outcomes as each jurisdiction has entered the NDIS from very different systems. The implementation challenges and outcomes are therefore different as are the appropriate policy and implementation responses. For example, the implementation challenges in the NT are very different to all other jurisdictions, given its vast remote areas and higher incidence of disability and its intersection with indigeneity.

SDAC data is also vital for measuring outcomes for people with disability, who will not be eligible for the NDIS. We know that the State and territories are each responding differently to their responsibilities for "Tier 2", so measuring outcomes through the SDAC will be very important in terms of optimising future policy settings for those not eligible for the NDIS.

The National Disability Agreement is currently being reviewed under a Study by the Productivity Commission. This Study is likely to lead to a very different National Disability Agreement, going forward, because of major changes as a result of the introduction of the NDIS.

The Coalition is therefore seeking a commitment from all governments that under the new National Disability Agreement there will be a commitment to the collection of the full SDAC every three years.

Further, the greatest value from SDAC will come from linking this data base to other data sets. The Coalition is therefore seeking prioritisation of the SDAC in the MADIP database.

3. Data from the National Quality and Safeguards Commission

Now that the National Quality and Safeguards Commission has been established, data from the Commission should be also be made available for research and linked.

The Coalition is seeking data from the National Quality and Safeguards Commission to be made available for research under the “Five Safes”. However, we note in particular that some of this data will be highly sensitive and so not all of it is likely to become available, as even with data aggregation, highly sensitive individual cases will need to be protected.

4. National Disability Strategy

The National Disability Strategy is aimed at making all mainstream services accessible and inclusive.

It is a highly aspirational document, covering: inclusive and accessible communities; rights protection, justice and legislation; economic security; personal and community supports; learning and skills; and, health and well-being.

The National Disability Strategy sets “areas for future action”, but because the Strategy does not include any adequate monitoring or performance benchmarks, it is failing to meet its very desirable objectives.

To close this gap, the Coalition is recommending that a key requirement should be for all mainstream services to identify people with disability accessing their services and, in order to align with best practices and the NDIS, this data should be collected in line with the International Classification of Function (ICF), rather than current practices which generally focus on primary disability types. Then the progress of people with disability will be able to be compared with the population as a whole.

5. 2021 Census

In line with the Coalition’s aim to capitalise on existing, large data collections to build a stronger evidence base, the Census clearly forms a critical role, because it collects information on disability and unpaid care work and because it is the basis for many ABS surveys.

We recommend that the current questions in relation to disability and carers should be retained, to provide essential continuity.

However, there is one major gap in this data. No available datasets have information about whether someone is an NDIS participant. While we recognise that collecting detailed information about NDIS-funded services and supports is beyond the scope of the Census, having one question about whether or not a person is an NDIS participant would greatly enhance capacity to understand the impact of the NDIS on a broad range of social, economic and health outcomes for

people with disability and families and carers and would provide the most comprehensive evidence yet about NDIS participants and the rest of the disabled and non-disabled population.

At the moment, there is no way to identify NDIS participants in large routine data other than that held by the NDIA. Being an entire population survey, the Census has the potential to rectify this.

The inclusion of one question on NDIS participation in the Census would be a major step forward in this regard, noting that linkage of NDIS data to Census data, routine administrative data and ABS surveys would provide even better-quality data and negate the need for the Census to include this additional question.

However, given current uncertainties about access to NDIS data, the Coalition is recommending that the Census should include an additional question to the personal-level data which identifies whether the person is an NDIS participant or not.

6. Other Disability Data (Market Stewardship and State Specialist Disability Services)

In the original Productivity Commission Report into 2011 on Disability Care and Support, scant attention was paid to market risks, in part because the Productivity Commission assumed that growth in demand would stimulate sufficient supply. However, the rapid build-up of the NDIS, the setting of price caps and competition for scarce resources from health and aged care is clearly leading to shortages in supply.

Therefore, a key risk associated with the introduction of the NDIS is the risk of market failure and thin markets. It is essential that data is collected to monitor these risks, including workforce needs and that this information is then made available so that potential providers can respond in as timely a way as possible.

There is also a need to collect and to make available data on any other specialist disability services, which may continue to be funded by either Commonwealth or State Governments when the NDIS is fully implemented, so that there is a comprehensive picture of all disability services. The importance of these services and, hence, this data collection will depend on the scope of any future National Disability Agreement.

What we are asking for

In summary the Coalition for Democratising Disability Data is seeking to build unity across the disability and academic sectors for:

1. The NDIA to make NDIS data available to Commonwealth (ABS and AIHW), State and territory Data Integrating Authorities, so that it is available for research to improve the lives of people with disability, their families and carers, under the “Five Safes”
2. All governments to commit to the full and ongoing collection of the Survey of Disability Ageing and Carers (SDAC), which should then be included in Commonwealth and State integrated datasets such as MADIP database
3. The National Quality and Safeguards Commission to make its data available and linked with the NDIS and other key databases, under the “Five Safes”
4. All services which people with disability access to collect data on users in line with the ICF, so that inclusion and access by people with disability, in line with the National Disability Strategy, can be measured and monitored for the first time, and

5. The next Census to include an additional question at the personal-level, which identifies whether the person is an NDIS participant or not.
6. Other data in relation to stewardship of the new disability marketplace and other disability services directly funded by governments to be made available for research.

Funding

Democratising Disability Data is vital to the future of people with disability, their families and carers, at this time of enormous change and opportunity.

The University of Melbourne is making a major investment in big data and, through MDI, the Coalition will have access to experts across the University, including international leaders.

Because of the central importance of this issue, the Melbourne Disability Institute will be investing \$50,000 and a further \$50,000 in-kind in support of the Democratising Disability Data Coalition.

Please go to <https://disability.unimelb.edu.au/research/democratising-disability-data> to register your interest.

Coalition Founding members:

